

The Role of Psychological Wellness in Type 1 Diabetes Management

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On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

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STS Research Paper

Introduction

People with diabetes are two to three times more likely to experience depression than people without diabetes (CDC, 2021b; Roy & Lloyd, 2012). This statistic suggests a link between chronic illness and mental health that should be explored more by the medical and scientific community. Despite considerable advancements in diabetes treatment, especially in technologies such as insulin pumps and continuous glucose monitors, standard diabetes treatment protocols are not yet complete. In order to provide the highest standard of care with the lowest chance of negative outcomes and complications, psychological evaluation, resources, and treatment must be provided to patients. The focus of this paper is on the treatment of Type 1 Diabetes (T1D), which is a chronic illness that currently has no cure and requires lifelong treatment and self-management. The constant need for disease management, along with societal misconceptions about diabetes, can have a psychological toll on the patient, in turn making it more difficult to successfully manage their disease.

The Science, Technology, and Society (STS) framework is used to analyze the issue of mental health in diabetes management is wicked problem framing. Use of this framework allows for the consideration of how the central problem and its possible solutions inform one another and cannot be considered separately. Because of the complex nature of health care systems and the protocols for dealing with incurable chronic physical illness as well as psychological difficulties, the consideration of different solutions further informs the definition of the problem at hand. Wicked problem framing allows for the perspectives of all involved actors to be evaluated, and the problem definition and proposed solutions to be continually reassessed in a process that does not have a definitive conclusion. Changes to standards of care must continue to

develop overtime according to new findings and discoveries in these relevant areas. Wicked problem framing is used as a tool to analyze the complex relationship between mental and physical health, as well as the feasibility of proposed solutions. The solutions proposed in this paper are intended to serve as future inputs in the analysis of this complex topic.

Research Question:

How does the psychological condition of Type 1 Diabetes patients impact their ability to manage the disease, and how can standard treatment plans change to take this connection into account and improve disease management?

Research Methods

The answer to this question is developed through review of existing literature on the state of psychological care in T1D treatment and the process of wicked problem framing. The literature reviewed consists of studies and articles related to symptoms of psychological distress and diabetes disease management. Wicked problem framing is used to synthesize the material and evidence gathered to reveal connections between the problem and its potential causes, as well as to suggest possible solutions. This kind of problem framing allows the proposed solutions to be formulated with the understanding that the relationship between the aspects of disease management, health care, mental wellness, etc. and the stakeholders involved are complex and should thus be approached with the intention to re-interpret this information. In according with wicked problem framing, these proposed solutions serve to further inform the identification of the problem itself.

Research for the literature review was conducted as a study of secondary sources of relevant topics in order to analyze the current state of discourse on the role of psychological state

and care in the treatment of T1D. These topics include background on T1D pathology, statistics related to diabetes management and mental illness comorbidity prevalence, current standards of diabetic care, psychological intervention programs for patients with poor disease management, and proposed changes to the standard of care. The evidence and analysis are presented thematically, tackling different areas of concern in diabetes management and mental health and proposing solutions accordingly, as well as somewhat chronologically, beginning with identifying patient distress and moving to treatment options.

Diabetes and Management

Type 1 Diabetes (T1D) is a chronic autoimmune disorder in which the pancreas is unable to produce the hormone insulin, which is responsible for important metabolic processes that regulate glucose levels (*Type 1 Diabetes - Symptoms and Causes - Mayo Clinic*, n.d.). In the US alone, over 37.3 million people live with a diabetes diagnosis, and about 1.4 million Americans are newly diagnosed with diabetes each year (*Statistics About Diabetes / ADA*, n.d.). While it is currently unclear what exactly the relationship between diabetes and depression as comorbidities is, the presence of a relationship is itself clear (Roy & Lloyd, 2012). The sheer number of patients living with diabetes and their increased likelihood to experience depression displays the need for improved standards of care and a review of what these standards should include.

One of the key tools in diabetes diagnosis and monitors of successful management is the hemoglobin A1C test, which measures an individual's average blood sugar levels over the past three months. A normal range is below 5.7%, the diabetic range is 6.5% or above, and a level of 7.0% or higher indicates increased risk of diabetes complications (CDC, 2018). 50% of US adults diagnosed with diabetes have an A1C value in this >7.0% category, indicating

unsuccessful disease management (*National Diabetes Statistics Report 2020. Estimates of Diabetes and Its Burden in the United States.*, 2020). Unsuccessful disease management over time can cause many serious complications, such as heart and blood vessel disease, nerve damage, kidney damage, and eye damage, resulting from intense fluctuation of blood glucose levels or sustained high blood glucose levels, known as hyperglycemia. Additionally, diabetics are more susceptible to serious complications of other illnesses, such as pneumonia (CDC, 2021a). Another more immediate complication that arises if blood sugar levels remain extremely high for a period of time is diabetic ketoacidosis. Without insulin, the body is unable to break down glucose to use for energy, and so it begins to break down fat to use as an energy source instead. This creates a buildup of acids called ketones in the blood, which causes vomiting, confusion, weakness, and can lead to death if left untreated (*Diabetic Ketoacidosis - Symptoms and Causes*, n.d.).

Managing T1D requires that the patient consistently monitor their blood sugar levels, activity levels, carbohydrate intake, and other factors that may not seem as intuitive, such as sleep, alcohol consumption, and stress. T1D patients require insulin injections in order to metabolize glucose, which can be delivered via syringes or insulin pumps. Blood sugar is monitored using either finger-prick tests throughout the day or a device called a continuous glucose monitor (CGM) that is attached to the patient's body and allows blood sugar levels to be read continuously. The need for constant surveillance and treatment is physically and emotionally demanding, and because there is no cure, the treatments must be carried out for the rest of the patient's life. Many T1D patients spend very little time after diagnosis without some sort of technological device either attached to or near them that aids them in monitoring and treating their disease. Additionally, this psychological burden is magnified by the social

implications of having this disease, as many people do not understand what a T1D diagnosis really means and may jump to conclusions about a patient's lifestyle.

The term "diabetes distress" has been coined to address the specific phenomenon of the emotional and psychological difficulties of living with diabetes, resulting in the development of the Diabetes Distress Scale (DDS) (Polonsky et al., 2005). The metrics on this scale include emotional burden, physician-related distress, regimen-related distress, and interpersonal distress. The Problem Areas in Diabetes Survey (PAID) was also developed to investigate the relationship between emotional state, coping mechanisms, and level of disease management (Polonsky et al., 1995). In a study of the reliability and implications of PAID by Polonsky et al, it was found that approximately 60% of the subject sample reported at least one serious concern related to diabetes, and there was a clear correlation between general emotional distress and long-term complications, negative self-care behaviors, and A1C levels.

Wicked Problem Framing

The research and analysis detailed here dives into the intersection of medicine, medical care, and disease pathology with society, social implications of disease, and societal factors affecting care and science. The issue of disease management procedures for T1D patients and the existence of "diabetes distress" exemplify how the physical and psychological implications of a disease cannot be separated. It is important to not only examine how the disease affects the body biologically, but also how societal implications and understandings of the disease affect patient well-being and self-management. Disease management cannot be simplified to biological management, due to the social reality of living with a chronic illness as well as the extent of what is required for healthy disease management. In the field of STS, complex problems that have no clear, singular solution and are inherently hard to define are often analyzed through the wicked

problem framework. This framework has been used to attempt to tackle the issues of sustainability in engineering and poverty in policy planning (Rittel & Webber, 1973; Seager et al., 2012).

Rittel and Webber, credited with establishing this framework in their 1973 paper, outlined ten distinguishing properties of what can be considered a wicked problem. Seager further reduced these ten to five essential characteristics, which are as follows: difficulties in problem formulation, multiple but incompatible solutions, open-ended timeframes, uniqueness, and competing value systems or objectives (Seager et al., 2012). Crucial to the conceptualization of a wicked problem is its inability to be succinctly or completely described and understood. The nature of a wicked problem requires steps toward a solution to be made before the formulation of the problem becomes fully available. This complexity leads to another established characteristic of a wicked problem: that there is no “stopping rule” (Rittel & Webber, 1973). When attempting to solve a wicked problem, there is no definitive point at which the right solution is reached and work on the problem is no longer necessary. These kinds of problems are constantly developing and changing, and solutions that are put in place bring to light more areas where change is necessary. In this way, attempting to define and solve a wicked problem is a cycle, one which must be consistently reevaluated. The complexity of the wicked problem framework directly reflects the complexity of the relationship between social and technical elements of our world.

Constraints of a wicked problem change over time, and stakeholders have differing ways of understanding the problems at hand (Termeer et al., 2019). Because of this, there is no singular “true” solution, but instead many possibilities that must be evaluated in comparison to each other. Difficulty in problem definition is demonstrated in the difficulty of defining the specific and concrete issue with current diabetes treatment that creates such high rates of

depression and poor self-management. Various perspectives surround this problem, including those of patients, endocrinologists, patients' loved ones, and psychologists, which must be considered in order to begin to untangle the relationship between mental health and physical health. One major difficulty in attempting to untangle this web is that living with diabetes comes with a myriad of psychosocial implications that may not be fully understood by these stakeholders, including the patients themselves (Nefs et al., 2012).

Critics of the wicked problem framework often take issue with the difficulty of both defining the problem and proposing a solution (Turnbull & Hoppe, 2018). To these critics, it seems that there might not be a purpose to classifying something as a wicked problem if it cannot be defined or there is no hope for a solution. Termeer et al. poses the question of whether defining a problem as wicked actually has any analytical use or provides new insight on how to address the issue (Termeer et al., 2019). While some see the complexity of the wicked problem framework as an analytical obstacle, others see it as a way to work with the full reality of the problem and the space it takes up in the social and technical world without forcing simplification. In response to criticism, Nance Roberts, a scholar in Wicked Problems and Organization studies, identified three specific strategies to work with wicked problems: authoritative, competitive, and collaborative (Roberts, 2000). Each of these approaches is different in the strategy with which they initially tackle the proposed issue, and together they demonstrate that wicked problems can be worked through with the goal of finding solutions. A wicked problem diagnosis is not the end to analysis or understanding, but the beginning.

Results and Discussion

The Relationship between Physical and Psychological

The relationship between mental wellbeing and diabetes management has been a point of discussion for decades (Rubin & Peyrot, 2001). It has been shown that not only are those diagnosed with diabetes 2-3 times more likely to develop symptoms of mental health issues such as depression (CDC, 2021b), but also that emotional and psychological distress, including diabetes burnout, contribute to poor disease management (Egbuonu et al., 2021). To address this complex issue, changes must be made to standard diabetes care in order to ensure that patients receive care that encapsulates and treats every aspect of living with diabetes. These changes can be classified into two broad categories: implementation of standards and processes in clinical settings and external resources that are clearly communicated to patients by their health care team. These two categories must be implemented together in order to effectively target and relieve the psychological burden that accompanies T1D management.

First the connection between mental well-being and glycemic control must be firmly established. In a study comparing objective measures of glycemic control in adult T1D patients with and without depression, as determined using the PHQ-9 depression screening questionnaire, it was found that depression leads to poor disease management in a myriad of ways (Egbuonu et al., 2021). Symptoms of depression, including depleted energy, trouble thinking and concentrating, and feelings of hopelessness and worthlessness (*Depression (Major Depressive Disorder) - Symptoms and Causes*, n.d.), cause patients to perform fewer blood glucose tests, miss insulin doses, exercise less often, and have poor regimen adherence (Egbuonu et al., 2021). Additionally, symptoms of hyperglycemia caused by this poor disease management, including tiredness and weakness, can exacerbate depression symptoms and thus create a cycle of poor management that is difficult to break (*Hyperglycaemia (High Blood Sugar)*, n.d.).

Because of these established connections between depression and poor diabetes management, the American Diabetes Association (ADA) Standards of Care recommends that all patients with diabetes be screened for depression, anxiety, and disordered eating annually (ElSayed et al., 2022). However, this recommendation is not a requirement in health care and diabetes treatment, and so it is unknown how many patients actually receive this yearly mental health screening. One simple, but possibly very effective, way to improve diabetes care is to implement annual screenings for these mental illnesses as well as diabetes distress specifically. There are several different tools now available for assessing diabetes distress (Fenwick et al., 2018; Polonsky et al., 2005), including the original 17-item Diabetes Distress Scale (DDS) (Polonsky et al., 1995), which is often used in research studies to determine baseline and subsequent levels of distress and psychological burden. The use of these standardized questionnaires and scales would allow for easy identification of patients that are at risk of or are already suffering from poor disease management as a result of their mental health. Because these questionnaires and metrics are standardized, widely used, readily available, and simple to conduct, theoretically there would be minimal burden placed on doctors and health care providers in implementing yearly screenings. Following wicked problem framing, implementing this kind of screening would serve to shed further light on the complex connections between mental wellbeing and T1D, in turn providing an opportunity to redefine the problem and work towards new solutions.

Addressing Distress

The next issue to address is how to treat patients that demonstrate high levels of distress that affects their disease management. Wicked problem framing allows for consideration of how complex factors inform each other and proposed solution, with the acknowledgement that no

single solution can address all issues present. When considering mental health factors, there are many complicated relationships with physical and mental wellbeing to be considered, including but not limited to mental illness diagnosis and age of diagnosis, substance use, antidepressant or other similar medication use, and whether or not the patient attends psychotherapy for mental health reasons. All of these factors may inform what course of action is necessary or recommended to treat distress related to disease management.

There are two studies of particular note that attempted to implement different strategies for treating diabetes-related distress (DRD) in an effort to improve disease management, as measured using self-reported data as well as A1C levels (Doherty et al., 2021; Raveendranathan et al., 2019). One of these studies, Raveendranathan et al., tested the viability and efficacy of a psycho-endocrinology liaison service within a clinical setting where T1D patients were first screened for diabetes-related distress using the DDS and patients showing moderate to significant distress, a mean item score of ≥ 3 , received a single 45–60-minute psychological intervention/counseling session with a psychiatric nurse on site. These sessions focused on providing the patients with education about diabetes and physical activity and medication adherence, along with relaxation techniques and illness-specific problem-solving strategies. The effectiveness of the interventions was assessed using changes in scores on a patient-rated visual analog scale, the Clinical Global Impression-Severity (CGI-S) scale, a physical activity questionnaire, and medication adherence at a baseline before the intervention and at a two-month follow up appointment. The CGI is a brief assessment of a clinician's view of a patient's global functioning before and after a treatment event (Busner & Targum, 2007), with the severity section evaluating severity of psychopathology on a scale from 1 to 7. Because this particular

study was conducted on a relatively short time scale, quantitative glyceemic control data such as A1C level was not collected as a measure of efficacy.

The Raveendranathan et al. study determined that psychological intervention is effective in improving psychological distress and therefore self-management practices according to the metrics previously stated. The DDS is divided into four subdomains, regimen-related distress, emotional burden, interpersonal distress, and physician-related distress (*Scales and Measures – BDI*, n.d.). It was found in this study that the most common DDS subdomain was emotional burden, further emphasizing the how immense the psychological impact of T1D can be on an individual. Overall, what was found most useful to patients in their intervention session was the time spent on learning problem-solving skills specific to dealing with diabetes management. This finding is not a unique one, as the Johns Hopkins Diabetes Center has a successful psycho-educational program for people with T1D to be trained in specific coping skills, combining general diabetes education with cognitive behavioral therapy (CBT) (Rubin & Peyrot, 2001). The Raveendranathan et al. study serves to demonstrate how psychological symptom monitoring and intervention can be effective as a part of routine T1D patient care.

It is important to consider the complications of the Raveendranathan et al. study, especially when analyzing it with respect to wicked problem framing. Self-reported data, such as that used to determine the results of this study, can at times be unreliable in absence of quantitative data. In the case of self-reporting psychological distress, patients may sometimes under-report their negative feelings and symptoms for various reasons, including not wanting to ask for help or believing that their amount of struggling is “normal” and cannot be helped. Response bias is an issue in psychometrics that has triggered the development of various tools to attempt to identify and remedy bias, such as stochastic frontier estimation (SFE) (Rosenman et

al., 2011). While the possibility of bias is important to consider, it does not mean that the results of this study are unreliable. Another important note about this study is that patients with diagnosed axis 1 psychiatric disorders, such as schizophrenia and anxiety/mood/sleep/eating disorders (Widiger & Shea, 1991), were ruled out of participation in the study. The complex interaction of diabetes and its management and diagnosed mental illness is something that is therefore not addressed. Essentially, the Raveendranathan et al. study offers a proof of concept of the efficacy of including psychiatric care in regular patient care, and this program should be expanded and studied with other varying factors, including a lengthened time scale, more complex mental health history, and more intervention sessions, perhaps of varying structures.

The Doherty et al. study investigated the feasibility of an online instant-message based therapy for those suffering from psychological distress related to their diabetes management. This treatment plan differs from the aforementioned Raveendranathan et al. study in that it is meant to occur outside of typical clinical care and consist of multiple sessions. Termed Diabetes Online Therapy (DOT), the treatment plan was 10 intended sessions of CBT-based treatment delivered by diabetes specialist nurses via a secure online real-time instant messaging system. All patients studied demonstrated poor glycemic control, as evidenced by an A1C > 8.5%. Patients we also evaluated using anxiety, depression, and DDS scales before and after treatment. DOT proved not only to be a feasible psychological intervention option, but also resulted in lower A1C levels, indicating improved glycemic control, and lowering mental distress symptoms in patients who demonstrated elevated levels prior to the onset of treatment. Through gathering this data, the feasibility of using a secure online platform like DOT for the collection of secondary outcome data, such as screenings for depression, anxiety, and DDS, was also verified. Based on the results of the studies previously mentioned, it can be concluded that programs

specifically meant to address the psychological burden that disease management places on T1D patients are effective in bettering glycemic control, and therefore improving quality of life of these patients.

In Newby et al. it was found that web-based CBT for patients with comorbid diabetes and major depressive disorder was significantly effective in treating depression, resulting in 87% of participants no longer meeting the criteria for major depressive disorder (Newby et al., 2017). However, there was no significant difference in patient A1C levels found as a result of this treatment. While the aim of this study was to evaluate CBT as a treatment option for patients with both depression and diabetes, the therapy given was not specifically tailored to the psychological burden of diabetes. CBT has thus shown to be a very effective tool in treating depression, including in T1D patients (Uchendu & Blake, 2017), but it is clear that in order to effectively tackle the issue of emotional and mental distress as a result of diabetes management the psychological treatment must be specialized, addressing the specific burdens and stressors faced by patients dealing with T1D. This is why integrating psychological screening and care into routine care is imperative to truly helping those suffering from DDS.

Improving Care

In comparing the types of treatments or programs outlined by Raveendranathan et al., Doherty et al., and Newby et al. above, it is important to note that having mental health care separate from diabetes care can be costly, time consuming, and burdensome for the patient. For this reason, it is important to establish an element of mental health care within routine treatment for T1D, which requires regular specialist doctor visits to monitor the disease and the patient's self-management ability. Creating formal connections between doctors and other health care workers specializing in endocrinology and psychiatry is a step that must be taken in order to truly

provide T1D patients with adequate care. In addition to routine psychological screening and care as a part of regular diabetes treatment, effort must be put into developing extra-clinical resources and programs, and they must be made accessible to T1D patients by their official care team.

One way to integrate mental health care with physical illness care, specifically in those with diabetes, using systems already established in health care, has been investigated by Schumann et al. in an inpatient rehabilitation diabetes consult service. People with diabetes are more likely to be hospitalized compared to the rest of the population, while also having longer stays, more clinical complications, and higher costs (Schumann et al., 2010). The nature of diabetes means that patients are more likely to develop vision impairment, suffer from cardiac events, and suffer from greater disabilities as a result of infection. Diabetics are overrepresented in inpatient rehabilitation settings; however, diabetes is often a secondary diagnosis to the acute event or illness that brought them into the hospital, and thus is rarely specifically addressed in the rehabilitation process. Rehabilitation psychologists that work with these patients during their inpatient stay are uniquely positioned to assess the functional, psychosocial, and behavioral needs of people with diabetes and intervene to improve self-management of their disease. In an inpatient rehabilitation setting, T1D patients have access to education and resources, specifically psychoeducation and psychologists, that they might not otherwise receive. Because these rehabilitation psychologists are already equipped to deal with the complex relationship between physical illness and mental wellbeing or distress, the basic infrastructure to provide diabetics with more complete care is already in place in this situation, it just requires special attention and direction to ensure that diabetes and its effects are not overlooked.

While it is important to develop ideal solutions for the problems described above, it is also important to recognize that all of the suggested improvements, even when combined, can

eliminate the problem entirely. In using wicked problem framing, often proposed solutions serve to further illuminate the problem at hand, or even create new ones. As is true with any discussion based on health care, it is important to note that access to care is not equitably distributed. The development of new programs to assist patients with diabetes distress and mental health as well as their integration into routine care does not address the issues of those patients who are unable to see a doctor regularly or at all, cannot afford medications or other treatment, do not have access to internet for online resources, or any myriad of accessibility issues. The actions proposed in this work are not meant to be comprehensive solutions, but rather important steps to be taken to alleviate some of the weight placed on T1D patients.

Limitations and Future Research

A major limitation of this work lies in the time constraint provided for research and synthesis of the very complex topic of the intersection of diabetes and mental wellbeing. As previously stated, the wicked problem framework is used to tackle this topic because of its incredibly complex and largely undissected nature. Research was limited in that there is a lack of long-term studies of how psychological intervention improves disease management over a period of time longer than approximately 12 months or rates of patient relapse to a distressed state with poor disease management. Additionally, there is a lack of a conclusive, universal, and agreed upon treatment strategy for the specific problem at hand, and so more work must be done in this field to determine what kinds of programs and treatments should be made available to patients. Overall, future investment in studying the intricacies of the relationships described throughout this work and the development of strategies and treatments with clear, evidence-based results will be of immense importance in continuing to develop solutions.

Future research on this topic should address equity in health care access and how this may exacerbate the problem even more. Included in this research should be a comparison of health care in multiple countries with different structures of health care and insurance in order to determine what kind of health care model provides the most complete treatment and results in the most positive outcomes. Additionally, it could be useful to hold a study specifically to compare the impacts of receiving help or treatment for diabetes-related psychological distress in a clinical setting versus utilizing resources outside of standard care.

Conclusion

There is an undeniable relationship between Type 1 Diabetes and mental health, so much so a new term has been coined to address the specific phenomenon: diabetes-related distress. In turn, it has been clearly determined that psychological distress often plays a role in poor disease management and glycemic control. To address this, steps must be taken to develop specific approaches and methods for screening and treating patients who exhibit these symptoms and struggles. Suggested solutions include regular screening for DRD and mental illnesses such as depression and anxiety as a part of routine T1D care in a clinical setting, closer relationships between endocrinology and psychiatry specialists, and the deployment of CBT-based intervention programs both inside and outside of clinical settings. It is important that once specific programs or treatment plans are developed, they are made easily accessible to patients by their care team. In this way, the largely unaddressed issue of distress and its devastating effects on diabetes patients can begin to be more thoroughly investigated and confronted.

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